

# Harnessing the Power of Parents to Change the World!

(Or at least improve your child's IFSP/IEP)



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# Today's presentation...

- *Make your efforts more effective in developing IFSPs and IEPs*
- *Step up from a "reactive" role on the team to the pro-active approach through the four "R's" of Advocacy: Reason, Rationale, Resolution, and Remedy.*
- *Know how to get meaningfully involved so your child can get the education s/he deserves.*

# The point of empowerment...



# Parents as Catalysts: The Power to Create Change

Parents can often do things on the 'outside' that professionals can't from inside the system.

- ♦ *No company line*
- ♦ *Fueled by passion & purpose*
- ♦ *A constituency that cannot be ignored*





# What are the burning issues for parents?

- Help, they want to put my child in a preschool for the disabled!
- Help, they tell me my son is not eligible for special ed. Because he's doing 'too well'.
- Help, my baby can't hear!
- Help, they've assigned a new interpreter to my daughter who uses ASL, and the terp uses SEE?
- Help, my school just assigned an SLP who has never worked with deaf kids, and my child just got a CI...
- Help, the school told me my daughter has to go the center based program/can't go to the center based program/has to go to the school for the deaf/never told me about the school for the deaf/has to go to the neighborhood school due to LRE...
- Help, the school says they can't find anyone to serve my child, even though they've 'advertised'.
- Help, my child has never learned any self-advocacy tools to along in the 'real world'.
- Help, my child is getting good grades but is really lonely and has no friends.
- Help, I think my child needs \_\_\_\_\_, but the school says no.
- Help, my child is in 6<sup>th</sup> grade and reads at the first grade level!

# National Statistics

- High school graduates who are d/hh: SAT-9 Scores - 3.9 Reading Comprehension; 5.0 Math' 4.5 Language; 6.0 Spelling (Bloomquist Traxler, 2000)
- Between the ages of 8 and 18, deaf/hh children gain 1.5 years in reading skills. (CADS, 1991-2)
- 30% of all deaf/hh children leave school functionally illiterate (Conrad, 1974)
- Only 8% of deaf/hh graduate from college (US Comm., 1988)
- 40% deaf/hh unemployed, 90% underemployed (Seigal, 2000)
- Colorado: Kids scores are improving (CDE 2005 Report)
- Iowa?: How are your kids doing? Collectively/Individually

# What are we going to do about this?

Learn the “Rules of Engagement” with Institutions

## Credible Presentation

- . From personal experience into collective experience
- . Mastering the “Elevator-handshake”
- . Be a parent, but be professional

## Legal Savvy

- . Rights and responsibilities
- . Documentation essentials

## Cultural & System Norms Navigation

- . Who's the boss?
- . What's the “company line” and why?
- . Integrate within the network

# Meaningful Involvement: Come Early & Come Often

- The Myopia of EHDI systems
- Transitioning to Education
  - What good does it do to send a child into the educational system with age appropriate language, if that system is only prepared for failure?
- Sometimes the best IEPs crumble if there's no "quality control."



# How do we move from “reactive” to “proactive”?

## Know your child.

- ♦ His/her hearing loss, its impacts & interventions
- ♦ What s/he ought to be capable of at this age
- ♦ Current levels of performance

## Know the law & your rights.

- ♦ IFSP & IEP process
- ♦ Deaf/hard of hearing specific applications
- ♦ Rules of engagement

# IDEA's *Special Considerations* for Students Who Are Deaf or Hard of Hearing

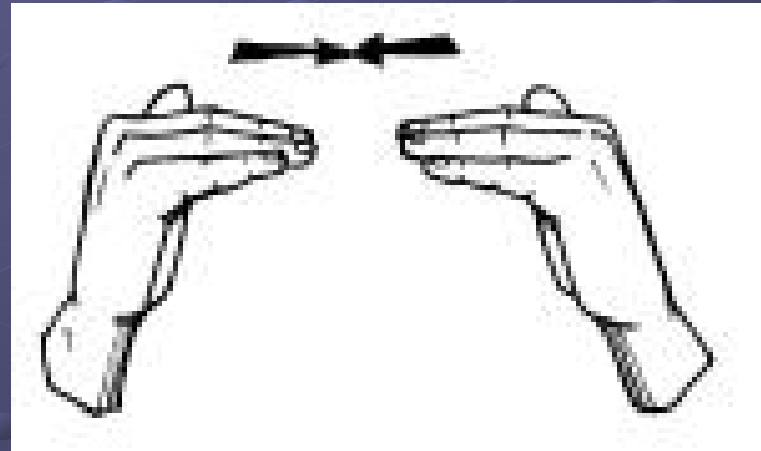
"In the development, review and revision of an IEP...consideration of special factors:

- (iv) *Consider the communication needs of the child, and in the case of the child who is deaf or hard of hearing, consider the language and communication needs, opportunities for direct communication with peers and professionals in the child's language and communication mode, academic level, and full range of needs including opportunities for direct instruction in the child's language and communication mode, and*
- (v) *Consider whether the child requires assistive communication devices and services."*

IDEA Sec. 300.324 (2) (iv)

# Level the playing field

- Discuss the real issues & strive for mutual good intentions and communication
- Give each other the benefit of the doubt
- Seek a neutral party/mediator
- Know what they know (Sec. 615 (b)(1) “the right to examine all records”)
- Know the legal remedies!



# Identify Areas of Disagreement

- Mode of Communication and/or Method
- Communication Plan considerations and/or implementation
- Student's present levels of performance
- Student progress toward goals
- Method of measuring progress and/or reporting progress
- Least restrictive environment and/or Placement
- Annual goals, benchmarks or short term objectives in what areas?
- Special education services to be provided
- Related services to be provided
- Supplementary aids and services
- Modifications to curriculum
- Supports from school personnel
- Qualifications/proficiency of staff delivery IEP services
- Student's participation in standardized tests
- Dates of services
- Transition services
- Behavioral Intervention
- Other





# IEP B i n g o

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"Sorry... we don't have the money."	"We're not convinced your child needs that."	"I have 400 other children in this building."	"We assess your child using only teacher observation."
"The general education teacher couldn't be here today."	"We're the professionals, we know what's best for your child."	"Let us get back to you on how that might work."	"I don't have the authority to make that decision."
"Your child is doing great compared to other deaf/hh kids."	"If you don't teach your child to sign, he'll use it anyway when he grows up. You better do it now."	"If you teach your child to sign, she will never learn to talk."	"We took the liberty of filling out a 'draft' IEP... please sign here."
"Your child will have to use signed exact English. We don't do ASL here."	"Your child is two years delayed in language... we can't really expect more than that."	"You must be in denial, your expectations are too high for your child."	"We don't need to write that suggestion down in the IEP, we'll do the best we can to get that done."
"When it comes to 'methodology', the school gets to decide"	"We do not want to put your child's primary disability as 'hearing loss'"	"Your child does not need an IEP, a 504 plan will work just the same"	"The law says that we don't need the general ed. Teacher here (or the SLP, or the Audiologist)"
"I'm sorry, the law now says we can not write short term objectives on the IEP"	"Anything related to your child's cochlear Implant is not our problem"	"Your child does not qualify for services, she is doing too well"	"Your concern does not relate to an academic objective for your child"

# THE IEP CHECKLIST:

## RECOMMENDED ACCOMMODATIONS AND MODIFICATIONS FOR STUDENTS WITH HEARING LOSS

at [http://www.handsandvoices.org/pdf/IEP\\_Checklist.pdf](http://www.handsandvoices.org/pdf/IEP_Checklist.pdf)

### Amplification Options

Personal hearing device (hearing aid, cochlear implant, tactile device).  
Personal FM system (hearing aid + FM).  
FM system/auditory trainer (without personal hearing aid).  
Walkman-style FM system.  
Sound-field FM system.

### Assistive Devices

TDD.  
TV captioned.  
Other.

### Curricular Modifications

Modify reading assignments (shorten length, adapt or eliminate phonics assignments).  
Modify written assignments (shorten length, adjust evaluation criteria).  
Pre-tutor vocabulary.  
Provide supplemental materials to reinforce concepts.  
Provide extra practice.  
Alternative curriculum.

### Evaluation Modifications

Reduce quantity of tests.  
Use alternative tests.  
Provide reading assistance with tests.  
Allow extra time.  
Other modifications: \_\_\_\_\_

### Instructional Accommodations

Use of visual supplements (overheads, chalkboard, charts, vocabulary lists, lecture outlines).  
Captioning or scripts for television, videos, movies, filmstrips.  
Buddy system for notes, extra explanations/directions.  
Check for understanding of information.  
Down time / break from listening.  
Extra time to complete assignments.  
Step-by-step directions.  
Tutor.  
Note taker.

### Other Needs? Considerations.

Supplemental instruction (speech, language, Pragmatic skills, auditory, speechreading skills).  
Counseling.  
Sign language instruction.  
Vocational services.  
Family supports.  
Deaf/Hard of Hearing role models.  
Recreational/Social opportunities.  
Financial assistance.  
Transition services.

### Communication Accommodations

Specialized seating arrangements:

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Obtain student's attention prior to speaking.  
Reduce auditory distractions (background noise).  
Reduce visual distractions.  
Enhance speechreading conditions (avoid hands in front of face, mustaches well-trimmed, no gum chewing).  
Present information in simple structured, sequential manner.  
Clearly enunciate speech. Allow extra time for processing information.  
Repeat or rephrase information when necessary.  
Frequently check for understanding.  
Educational interpreter (ASL, signed English, cued speech, oral).

### Physical Environment Accommodations

Noise reduction (carpet & other sound absorption materials).  
Specialized lighting.  
Room design modifications.  
Flashing fire alarm.

Source: Johnson, Benson, & Seaton. (1997). *Educational Audiology Handbook*. Appendix 11-A, p.448.  
Singular Publishing Group, Inc.

# The Four R's of Advocacy

1. Reason
  - What's the motivation behind your reasonable request?
2. Rationale
  - Why should anyone agree with your position?
3. Resolution
  - How are you going to answer the questions that will come up?
4. Remedy
  - When the procedural safeguards and law come into play.

# 1. Reasonable Request

## ● What do you want for your child?

- “We’re requesting that the school (do/consider/implement/trial/assess) \_\_\_\_\_ for our child because...”
- Presented verbally, and in writing, ahead of time. Let the team know ahead of time that you’ll want time on the agenda to discuss this.

## ● Is your reason based on logic or emotion?

- logical arguments are easier to concede
- emotional appeals usually contain elements of logic, and should be articulated thus
- Effective advocates filter through the emotion & get to the logic



## 2. Rationale

💧 Support your reasonable request with irrefutable justification that has considered...

- “scientific, peer-reviewed-research-based” intervention
- expert testimony
- why you think your idea will improve your child’s performance
- what evidence you have that it can work
- your child’s assessments & evaluations and their implications
- The letter & spirit of the IDEA
- Can the opposing view be discredited?

💧 Ensure that your rationale is not just a restatement of your request!

# 3. Resolution

- Have a plan (solution) prepared in the event the school says 'no' to your reasonable request.
- Your solutions answer the questions they have, and solve the problems they think they can't surmount, (whether they've thought of them or not!).
- Who will be responsible for implementing the plan?
- All solutions are evidence-based & legally supported by federal and state laws.
- Know your line of compromise.
- Document your solutions! See forms on H&V website, search for "PEI Attachment" or downloadable documents.
- Check the resources at [www.handsandvoices.org](http://www.handsandvoices.org)

# 4. Remedy

Commit yourself to manage the quality of your child's education.

Educate yourself on special education law, (IDEA, NCLB, ADA), on your child's special needs and **use the Procedural Safeguards designed to protect your rights.**

Follow the first three R's Method of RAdvocacy.

**Prepare for litigation so you won't have to litigate.** (*Peter Wright, Esq.*)

Connect with a deaf or hard of hearing adult role model or mentor for opinions and advice.

Have a plan for full communication access during all parts of your child's school day (even extra-curricular school events) clearly written into his/her IEP.

**Have direct communication with your child's general education teacher, as well as every other professional delivering the services on his IEP.**

Network with other parents, especially in your own district, of deaf and hard of hearing students, for information sharing, and to use the power of numbers if needed.

**Make an ally of a professional on your child's IEP team.**

# 4. Remedy (continued)

- “Remedy” is the legal recourse

- Mediation
- Complaints (for non-compliance)
  - Must include statement of alleged violation, relative facts, not more than one year from filing
  - LEA has 60 calendar days to carry out investigation, gather relative info, issue a written decision
- Due Process (for non-agreement)
  - An impartial hearing of the issues
  - Engages “Stay put” in current placement
  - Don’t do it without representation

- Prevent the need for legal remedies

- *“prepare to litigate so you’ll never need to”*
- If it isn’t in writing, it never happened
- Unite with other families for strength in numbers
- Bring in an advocate
- Establish an ally on the inside
- Become the expert you need to be
  - In your child and in his/her “disability”
  - In the law



# Tactics

- The Cookie Mom
- Parents From Hell
- Parent, Ph.D (Parent wHo knows Deafness)
- The Parent as Team Manager
- Parents from Law School
- The Political Parent
- Parent as Lobbyist
- The 007 Parent

# United Efforts = More Impact & Effect

- 1 Parent: A fruitcake
- 2 Parents: A fruitcake & a friend
- 3 Parents: Troublemakers
- 5 Parents: “Let’s have a meeting”
- 10 Parents: “We’d better listen”
- 25 Parents: “Our dear friends”
- 50 Parents: A Powerful Organization



“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it’s the only thing that ever has.”

- Margaret Mead

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What makes the choice  
work is what makes  
the choice right. <sup>TM</sup>